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ABSTRACT

The paper describes reactions of an Israeli visitor to special education and rehabilitation facilities for mentally retarded persons in the United States and Canada. Among programs visited were group homes, infant stimulation projects, citizen advocacy approaches, and camps. Impressions are summarized, noting the trend toward deinstitutionalization, commitments to political advocacy, emphasis on citizens' rights, and the general inadequacy of workshops. The existence of four basic amenities in the United States--phones, cars, holidays, and adequate incomes--are missing in Israel; the effects on services are noted. A brief summary of services for mentally retarded persons in Israel concludes the report. (CL)

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REPORT ON A VISIT

TO THE UNITED STATES AND CANADA

TO LEARN ABOUT FACILITIES AND PROGRAMS FOR PEOPLE SUFFERING FROM MENTAL RETARDATION. from 18 May to July 12,82.

by Chanan Aharoni, Hedera , Israel .

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Summary of main impressions.
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C. Aharoni
Hedera P.o.B.241,Israel
August 2o,1982

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Chanan Anaroni
Herzlst.42,Hedera 3842I,Israel

August,5,1982.

My dear friends,

this letter has a double purpose : a) To say you once again "Thank You " for the extraordinary friendly way I was received by you when I recently visited at your place;
b) To give You a short summary of my findings during my recent eight week long study tour.I feel that on your vast continent many important things taking place in one area are sometimes not known in other regions.My Report could therefore,fulfill some service of messenger.

I) My tour started in Philadephia where I visited with the guidance of my friend Fred Toff the ELWYN Facilities on the I9 th of May. This nearly hundred years old Institution has developed extensive modern day care programs for 3oo students at age 6 to 4o years as well as good residential facilities for cca.6oo people in all age groups and with various handicaps.

Of special interest was the visit to the Child Development Centre in the nearby town for age 0 to 5 which is managed by Elwyn for the Delaware County.In addition to the kindergarden five instructors visit regularily 45 homesand try to teach parents how to care better for their handicapped children.

2) The next day we revisited KenKrest Facilities (I was there ten years ago)and found here nine recently built residential units,each for eight adults and the family of the house manager living in. Most of the 72 residents previously had been living in a big house which ten years ago had been used as an institution. All residents are working in sheltered workshops,none in the community.Seven staff people are working in each home.

The horticultural workshop in which I7 residents work needs a special mentioning,because it does also some gardening contract work in nearby towns.

Later we visited another workshop in Norristown which is caring for IIo clients.The costs per person per day are cca.$25 of which $ 2o are covered by grants.They managed to make ten placements in the community during the last year.

3) In the late afternoon we visited three new residential flats, each for 3 - 4 people,all in a private housing development area of a few hundred flats. The rent is 450.$ a month. Whilst the costs of one resident in a state Institution is 5o,ooo to 6o,ooo dollars p.a.the total cost of living in a flat incl. workshop is less than 5o % of this.Most of the people living now in these flats came during the last I8 months out of Penhurst,and inspite of their advanced age (3o -5o) remarkable progress has

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been made in behavior and self skill activities.I was invited to dinner and had a good opportunity to chatt with the ladies.One lady-counsillor lives in,another comes to relieve her on weekends and evenings off.The residents help more and more in setting the table,washing up and cooking. The salary of a counsillor (who all have some universitydegree in spec.Educ.,social work or psychology is 9000 to ten thousand dollar.A reliefworker gets 3,8 to 4 $ per hour. All the flats are richly furnished.

4) In Burlington - Vermont I visited a regional Infant Centre. There are 8o childrenat age I to 5 years involved.Most come in dayly for short sessions of 2½ hours in two shifts.Two normal childrenplay together with 8 subdeveloped children.One teacher and one practical aid work with each group.2 Physiotherapists and 2 occupational therapists of the nearby Hospital come in one special contract.

In the State of Vermont each year mass screening of all children at the age of three years are taking place in order to pick up those children who need stimulation and special help.Only some of the padiatricians have made good progress in their knowledge of what should be done for retarded children at the earliest moment;but even to-day quite a few medical schools still don't pay enough attention to the importance of this kind of stimulative and supportive work so important for the whole family. 50 % of the children attenting here are later placed into ordinary kindergardens,some with special aids paid by the school Boards.

5) From Mrs.Kay Stambler I learned about some other outstanding arrangements in this small State of Vermont! RESPITE MONEY :Parents of severely retatted children may easily get financial help ($ 3 per hour) for engaging a professional home help in order that they may enjoy a theater performance,a day off or week of vacation. This is Federal Grant money administered by Mental Health Commissioner.

The Exodus of retarded children from the institutions has here progressed so much that no children under age I6 are left in Vermont institutions,and no more children are accepted into them.

Retarded people coming out of institutions may receive a special loan of $ 2500 without interest for ten to twenty years in order to prepare for them residential homes.This moneu is administered through the Developmental and Disabilities Council,existing in every County.It is made available according to the Law 94/I42 which says that every handic. person has the right to live in the least restrictive environment.

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Children must go to special schools only if they can't go to ordinary classes.

6) Kay Stambler is a strong believer in MAINSTREAMING and the following is an incomplete summary of her arguments :

a)An enlightened teacher can in an ordinary class turn most of the 26 children into teachers and helpers of the one or two severely handic. children in their class.

b) These two severely handic.children make friends with ordinary children,must make efforts to compete in certain areas of daily life with ordinary children,and can achieve in this way real progress.

c) All the children of this class and their parents thus have some actual experience how handic.children act and what they really are, and they at least later on in life will not help building fences of segregation ,out of sheer ignorance or prejudice.

d)The severely handic.child is here perceived first of all as a human being,and this by its peers ,his teachers and later by the parents and a big part of the community.

e) As in special schools the ratio of staff to pupils is I:2, it would be much better to make this additional staff available to the children in need of help in ordinary classes.

f) The additional staff in special schools are often bored with teaching the backward children and are repeating the same kindergarden stuff year after year.This just could not happen in the ordinary class, because the children would make a row !

Against these arguments for Mainstreaming I would like to mention:

a) You must have some extraordinary and very strong parents to start fighting for it,and keep going on fighting year after year.

b) You must have some very enlightened Superintendent of schools and very devoted and capable teachers in order to carry it out and successfully overcome daily unforeseen difficulties.

c) You must provide well trained aides and all the paramedical staff necessary within the ordinary school.

d)You have to create a strongly positive atmosphere around these children in order to overcome antigonistic opinions of backward parents,public personalities and budget providers.

e) You have to fight for it year after year again.

f) I am not yet convinced that severely handicapped children can make better progress in a class of 26 -34 normal children (even when they get special help)than in the quieter atmosphere of the special class with Io to I2 children.

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7) In Burlington I had the privilege to participate in a 5 - days P.A.S.S (=Program Analysis of Service Systems) workshop. This was a unique experience of intensive,day and night long learning, discussing and gradually establishing a realistic technique for accurate assessment of Services for the Devaluated (Retarded,old people,mentally disturbed etc.).This technique is taught according to a convincing and systematic philosophy developed by Dr.Wolf Wolfensberger and written down by him in two books which make no easy reading.

About 36 people,mostly younger workers in the fields of special Educ.,social work and Mental Health Agencies,but also some parents took part.We heard introductory lectures together,but each day we split up into five permanent groups in order to discuss the issues and the tasks coming up.

After going through two simulation projects (a Home for the Old existing in Canada and a residential Home for the retarded at the edge of a big city)we prepared for our real task to assess a Home for emotionally deeply disturbed children.We visited there three times:a)To get the Management's philosophy and explanations; b)To see and speak with the children and the staff;c)to bring back our considered opinion about their efforts - through the mouth of the group-leader only.

I think that every person active in the provision of services for people in need of special care should participate once in 5-6 years in such a workshop,hundreds of which have been held during the last ten years all over the United States,Canada and recently also in England.

In order to give an example what this PASS workshop is all about,I want to describe one aspect only how we prepared ourselves before our visit to the institution.For three hours the members of the group asked themselves to mention items of childhood memories: Fights between brothers and sisters,holidays,the amount of privacy granted at home,simulating illness at school in order to go home earlier,skating,dating,peeping into parents room,dances,falling in love with the teacher,pocket money,birthday-parties etc.etc. All the items mentioned were written down on big sheets of wall paper and finally I counted 130 such items !

Then we asked ourselves the one big question.: How many of these childhood experiences are existing also for those kids living in the institution to be visited ? Or in other words !

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To what degree does this institution succeed in providing real childhood experiences to the children living within its walls ? We were very sad indeed when we learned that nearly none of the I30 items written down were existing in this Home which catered for 2o residential and ten daily incoming children. We wondered if the Manage ent and the teachers of the children asked themselves ever: What are the needs of ordinary children in daily life ? No wonder that thse kids quite often made attempts to escape; that they hated being there, and that apparently there was no central personality on the staff whith whom those children could identify.

8) I have, however, to make some remarks regarding PASS workshops in general: a) It would be important to keep contact with the thousands of people who have already taken part in such a workshop. Without strengthening and reinforcing the attitudes developed in the workshop these will fade away, earlier or later. Most of the participants return to their daily activities, having the excuse that as individuals in a complex administrative setting they cannot change anything. There should some effort being made to build a group of devoted people ready to fight for more human attitudes and more services directed toward better answers to real needs and realistic expectations .

b) There is no doubt that the philosophy of what is really important in serving the needs of the needy changes over the years. There exists the danger of developing different goals or giving different importance to the various items examined and evaluated. It seems therefore also from this aspect worth while to keep contact, to call people back for further workshops and to endaveour to establish coherency among the drifters.

9) When a guest on his farm in the Mountains of New Hampshire, my friend RICHARD SANDERS, Ph.D., Psychologist showed me round the great schoolsystem of Littleton, N.H.

The centre for multiple handicapped children we found integrated within an ordinary school. Children of the 6. Grade spend each day i - 2 hours as tutors with handic. children, and thus some of the aims of mainstreaming are achieved. Speech therapists and other specialists needed are a part of the school team and there is no need to fight for them or to pay for them privately. Buildings and furnitures as well as all kinds of special educat. or therapeutic devices are plentiful and of high quality -although this is a very small town.

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We visited also the regional sheltered workshop there which caters for 28 people and has some very good connections with factories,so there is a good variety of well paying jobs available.The workshop exists already seven years and is due to move soon to even better premises.It is managed by the North Eastern Regional M.H.Service. The parents are not much involved and no academic learning is taking place.

IO) In SYRACUSE,N.Y. I was the guest during the I.-3.June of Dr.Wolfensberger,whilst his wife Nancy showed me around.
We visited the rather modern Syracuse Developmental Centre which is really a big institution with very clean,wide,but dark corridors, a lot of fancy devices and instruments.Most of the children present here to-day.are severely and multiple handicapped.There are still 45o Residents here.Many have been released as cured into the community,but apparently -acc.to some pictures I saw = some aren 't looked after properly. About 5o Fostergrandparents come in daily,and each of them look after one or two children. Some critics say that only poor people qualify for this work,which remunerates with some meals,transport and a modst salary.I think this can be a very good relationship for all three sides,but could be enlarged also within the community.

During my visit there a three day course in self defence (!!) for the staff took place,and I heard some very critical remarks about this.It was further argued that the Medical Model still prevails in Government Institutions and this leads ultimately to Dehumanisation. Medication is still very important and taked the place of more active participation of the clients.The importance of work for each client acco to his ability is well understood,but the lack of remuneration for the work done by clients within the walls of the institution puts serious breaks on his therapeutic value.

Quite a few adult clients take part in an interesting educational programm within the Community College,3-4 times the week in the evenings,(See further on).Every two months a Dinner Dance Party takes place where staff and clients have a lot of fun.Also quite a few birthday Parties are arranged,if possible with family involvement.I was told about the difficulty to get good attendants (Male nurses)Many of the Applicants cannot write or speak properly!

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II) At noon I visited ONANDAGA Community College where exists since 1979 a special Department for develpmental disabled Adults.Everybody may come and take courses,like in an open University.This semester they had 125 students.1/3 of them take more than one class.80 % of the students are mentally retarded,or suffering from Cerebral Palsy,Epileptics,hearing or speach impairment.

The subjects include Reading,basic Mathematics,cooking,horseback riding,sexuality and many more.Each semester lasts for ten weeks; some classes are held here outside of town,other ones in schools in town. Each class has 5 - 10 pupils only and for each two pupils there is an aid in the class (University student) .

Up till now this department is still on probation and not yet an organice part of the Community College;therefore financing is difficult.(Partly through the S.D.C. mentioned earlier.) However, I was much impressed by this new development under the leadership of Mrs.Sue Lehr.

12) In the afternoon I visited three group-homes managed by the A.R.C. Two homes were built quite recently with a Government Budget, each for seven handicapped persons and a family living in.All r residents go to the sheltered workshop.There is additional kitchen staff and week end relief.

Social Security pay each resident 500 $
From an additional section 8 Grant:100
Total : $ 600.- From this sum only $ 55 are given the resident as pocket money,all the $ 545. go for his upkeep in the home.The staff must drive the residents into the workshops,because there are no buses.The annual expenditure of the home is 90.000 $ or $ 13.000 per resident. The cost of building the house were $ 130.000 with 12 rooms.

Most of the clients come from the State institutions and there is a great need to teach them self care and other elementary skills. The behavior of a few is still bad,and some don't know yet what is allowed or forbidden in such a home.Five residents are at the age of 40 - 65 years.Two clients with age of 20 - 25 years with some disturbed behavior.

13) In the second flat visited we found a couple of young people in charge of the home.He got a salary of 1080 as manager,his wife $ 8000, as assistant,and there is another help with a salary of $ 6900. The seven clients here come also from a State Institution;most are not verbal,one in a wheelchair.Some need help in dressing,one is not yet fully toilet trained.One girl bites other people when angry. All make good progress in their behavior,but in the meantime they don't help with home chores.

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In the third home which exists already four years in an older two storey house whithin the town I was invited for Dinner. Here all of the clients are much more independent, and the conversation flew freely during the dinner. In their free time they go to the YMCA, to basketball plays, for a walk, visit their family etc. Now they are planning their vacation.

I4) In Syracuse University I gave a small lecture with slides about services for the Retarded in Israel. There were not too many in the audience as only short notice for the lecture could be given, and at the same time in Boston took the annual Convention of the A.A.M.D. place.

There exists a l'arche Group in this town who live in two group homes, seven handicapped people with 3-4 other members.

I met also with the Director of the ADVOCACY BUREAU. This work is based on a Federal Grant, but apparently during the four years of existence of this work here occurred many difficulties: Only twenty matches could be made during the last two years. Ten of these for people who are still in Institutions and who don't have family contacts.

Whilst building one of the group-homes the neighbourhood revolted and took the case to court. They lost a lot of money and in the end they did not succeed; but in the meantime the opening of the Home was delayed for nearly three years.

I5) Prof. Wolfensberger publishes in his Training Istitute Toronto a bi-monthly paper which brings some very interesting news and articles regarding Normalization, Institutes, Citizen Advocacy and other subjects regarding courses of Pass workshops etc. There are also quite a number of interesting books available for sale in this Institute.

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In the State of New York (with a population of I8 millions) there exist I9 State Institutions with II ooo clients in them, whilst 2o years ago there were I9 ooo people. Taking into account that during all these years many more retarded people were born, these numbers prove that great efforts are made to move clients out of institutions into group Homes, for 3 to 8 people, into individual apartments, but also into not so good "Residential Homes "under private ownership und poor supervision.

I6) In Atlanta , the Capital of Georgia (6Millions inhabitants) I saw some facilities as guest of the Georgia ARC Annual Convention: Three new group-homes each for four clients, an occupational centre, a new kindergarden. Within the Metropolitan Area of Atlanta there are very good services, but in the country districts these are still much less developed.

The building cost of a home for 4 people were $ I6o,ooo.
A day at the occupat.centre costs $ I8.
" " Group Home " $ 39.or $ I6,ooo per annum.

I7) With my host, Mrs.Robyn Berger (a past President of the G.A.R.C.) I visited one of the finest Develp.Evaluation Centres in the States, under the Direction of Dr.Duan Blackstone who I5 years ago has laid the foundations of this excellent facility. The Clinic belongs to the De Calb County (½ Million Inhabitants) , but serves two further counties. Each year more than 4oo Children are seen here and their parents get advice and practical help. Each week Io to 2o children are screened. All the Maternity Homes in the surroundings give early notice; a specialist nurse makes first careful contacts with the family in their home. Very modern instruments for hearing and seeing impairment Diagnosis are used for every child, and excellent instructors work with children and their parents. On visiting here you feel the personal attention and love emanating from every member of the staff.

Twice a year Dr.Blackstone is arranging workshops for all the professional people and interested parents for one or two days with experts from all over the States. He is quite proud that the usual 5o % of unknown etiology in ret.children are reduced in his clinic to 25 % only. Due to this refined diagnostic technique his workers are able to start helping the children with more certainty and better prospects for success.

I saw here a beautiful girl of 2½ years after a spina bifida operation walking quite well with some help. She spoke fluently and her brain apparently was not affected. Dr.Blachstone thinks that true autism is caused by biochemical impairment, and that too many children are wrongly called autistic.

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He stresses the importance of Speech therapy being done with the whole family;after all they are in immidiate contact with the child at least ten hours every day,and they should thoroughly understand the importance of the exercises and how exactly to speak with the child !

I7) In a short talk with TOM GRAF ,the executive Director of the G.A.R.C. (24 years active in this work),I learned that great efforts are devoted to explanatory work with the Legislators and Chief Officials, because most of the money comes to-day from Federal and State Grants.

About IOO,ooo children in Georgia are in special Education;three years ago 2o,ooo parents were organised in the Arc;In the city of Atlanta they have 24oo members.

The Association has created a mobile Propaganda Unitwhich moves the whole year round and gives talks to thousands of children and citizen groups.They now prepare a Video film on M.R. for High Schools. I received here some very detailed Reports and action Plans. Thank You again, Tom !

I8) CITIZEN ADVOCACY. After a talk with DON TRITES who is in charge of the Citizen Advocacy Bureau in the State of Georgia. This idea came up ten years ago when Dr.Wolfensberger was visiting scholar in the Institute on M.R.in Toronto.It is the intention to find for each needy m.r.person a contact person in the commun.ity who is not exactly his legal Guardian,but helps him in all important and less important matters.Urgent needs for C.A. come up all the time in moments of severe crisis when no functioning parents or sibblings are available. A special friend is needed to help ret.people to leave the institutions and to establish and accompany them in the community,regarding dwellings,jobs and free time.

Since then Hundreds of such matches in many cities have successfully been made,but many matches also broke up out of a variety of reasons:Change of address,death of one of the partners, unsufficient preparation or help to the advocate.Even when we find people with good intentions and a warm heart:They usually are not ready to fight for their ret.friend alone against the whole world or the municip. burocracy;they need some professional guidance how to act in each specific problem.Therefore in each area Advisory Boards of some I5 Personalitites have been created,including Advocates,Physicians, Social workers,Psychologists etc.who are ready and qualified to give advice and help to advocates in handling special problems.

There exist also support groups where problems of common interest are talked over and thus the general publi gets some more information about this very important kind of voluntary help.

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Talks to groups like Rotary, Church groups, Bne Brith etc. make the programm better known, but in this way it is not expected that new volunteers will come forward . New Citizen Advocates are best recruited one the I : I Base! One Advocate tells a potential one about his personal experience and the deep satisfaction and success he has personally experienced by this work during the last year.

In each County they have a small Office and a contact person, and according to his quality they succeed to make more (or less) new advocates during each year. Financially this work is based on a federal Grant. In one town they have 40, in another 65 and in a third town they have now 100 active matches going. There is always a lot of delicate professional work necessary in order to straighten out small dificulties; otherwise these grow and become unsurmountable obstacles ! No dramatic results should be expected, but great improvement in behavior and life enjoyment occur all the time.

Don Trites was our lecturer in the PASS Workshop in Burlington; so there are good connections between various branches dedicated to improving living conditions for M.R. people in the community.

Here I heard for the first time about the SHANT Operation being now done quite frequently in cases of Hydrocephalus.

19) In LOS ANGELES I revisited (I was there ten years ago) some of the greatly enlarged and improved facilities created by EXCEPTIONAL CHILDREN FOUNDATION , under the able leadership of Dr. Robert Shushan.

The ART CENTRE (with Wilma James as Director) caused my admiration already ten years ago. To-day 80 people are coming here daily as to a sheltered workshop, and each one is guided to find his personal way of artistic expression, if by painting, drawing, carving, weaving or working with other materials. Some are so talented that they earn their living by selling their works; but each one gets some satisfaction out of his work. There is also a special room for physical training with an unbreakable Mylar (Plastic) mirror.

About a new branch of activity Infant Stimulation Centres, I got some information from Fran Chasan. The Los Angeles County is the biggest in the U.S. with four million inhabitants. The E.C.F. is managing with Grants for the County seven centres which are visited by 117 children and their families. Instructors visit the homes of another 20 children . A really deep impression I got by watching a special nurse in action during a two hours session: 8 children at age 2 to 5 were sitting with their mothers on carpets around the nurse who was aided by three half professional helpers. The nurse was kneeling in the middle , and whilst singing with all together children rhymes, was turning once to this child, and then taking into her hands another child,

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always moving,laughing,talking,singing and teaching the mothers by her example.At least three of the families were of Cuban origin and didn't understand a word of English.So every word was immidiately translated into Spanish.

One condition of attending these educational sessions is that the mother of the child must attend by herself each week at least one such session with the nurse in order to learn from first hand how to play and how to teach her own child.A second time in the week the parents meet with a social worker who naturally also must speak Spanish !

This atmosphere of educational play,singing songs and making movements with each child and at the same time teaching mothers and sisters how exactly to hold and move their handicapped children was perhaps not the way how physiotherapy is taught in the College; but it surely created a positive reaction in reeinforcing the stamina of the family to try at home to copy what was learned here.

This is one of the important goals of modern therapeutic work: To transfer sad,exhausted and pessimistic mothers into therapeutic aids who will continue every day to do the same exercises and stimulati.. play as learned here.

When mothers come for these sessions with their handicapped children, they bring their other children with them,and for these a special playing ground has been prepared.School buses bring them here and later also to their home.

Fran Chasan would have liked to do more work in Research and Documentation on the practical work done in the centres;but also in the States great cuts in Grants are lately made everywhere.
It is everywhere difficult to get physiotherapists,but there are enough speech-therapists.All the complex needs in special education are covered by the official school programm for all children from 4,9 years onwards;for specially handicapped children from three years onwards. She mentioned that MAINSTREAMING does not work except with specially motivated teachers;but they try now the opposite way :They accept normal children - sibbling into the the special classes !

20) Mr.JERRY FLUSSER who is Mr.Shushan's Deputy and works in programming for the retarded already 24 years,explained to me that all children coming into their programs are going through a thorough audiological examination.

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In California were a few years ago still Io - I2.ooo persons in Institutions;when Mr.Reagan was Governor here,he intended to close all these,but the Parents Organisations did not agree to this. To-day there are still 8.ooo people left in institutions,but at least the rate of intake has gone down,mainly due to the many day-care programms which enable parents to keep their children at home.

Quite a few of the mothers of small children in day care centres are by themselves teenagers;others are crazy about calory reckoning and thus deprive themselves and their embryo of essential protein nutrients ! Others got Rubella whilst pregnant and thus their children suffer from impairments of sight and hearing. Many are South American Immigrants.

2I) The Institute ON MENTAL RETARDATION in TORONTO is a unique creation of Dr.Allan Roeher,its first Director who conceived the need for a thoroughly founded,independent and well equipped Resource Centre in I963 and succeeded to sell this idea to the Kinsmen who donated most of the money for building the house.

To-day this Institute is well staffed with 4o professional workers;but Dr.Roeher again is not satisfied and intends to build some more,similar although smaller Institutes in other parts of the world.He started with a donation from the Canadian Government in the Carabbean Area;succeeded to inspire New Zeeland to build a similar Centre,thinks that Australia needs such an Centre and speaks also about Israel ...

The task of such a Centre is not to carry out Research,but to help in dispersing all the knowledge which is already available;to maintain a small,highly qualified staff capable of arranging workshops and seminars in his area,and naturally to build up a good library.

During the few hours I spent there on the June I4 I met with quite a few people , and learned that among other topics the Institute is active as

I) a National Reference Service:It gives answers to questions regarding M.R. which are sent here from all over the world.

2) as a Film Library. 3) an ordinary Library.

4) The Producer of films,like"Breaking Through."

5) PASS Workshop training Centre for Canada. 6) Program Coordinator e.g.advice and certifying curriculi on M.R. for courses of nurses etc.

7) Citizen Advocacy advisers; 8) Legal Advisers who prepare a new charter of rights,among other tasks.

9) At this time the whole Institute is extremely busy in preparing the World Congress which takes place just now there !

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22) In Toronto I met according to my request Mr.PETER DILL who worked for many years in the Institute and now is in the Metropol.Toronto A.R.C. Among his other activities he is the organiser of a Parents Study Group which meets on a purely informal and voluntary basis.I5 families with retarded children meet and tell their personal story;discuss their problems and thus help each other.They get immidiately involved,if a new family becomes known to the group or applies for some contact.

Easy ? Very neccessary ? Successful ? Right; but in the whole area of Toronto only one such group exists,this one Peter Dill is working with.Whoever has tried to organise such a parents group, and has succeeded to keep it going for more than three meetings, knows well that it taked a very good organiser,or psychologist or sozial worker to keep such a group alive.

23) Mrs.Sandy Keshen,my host in Toronto,is the energetic and successful Organiser of REENA FOUNDATION ,a Jewish group managing a flower workshop,5 Group homes,I8 supervised apartments and ten apa rtments for ten retarded people who need very little help indeed. A total of 58 people are cared for,and in the summer months REENA operates a beautifully laid out SUMMER-CAMP for Youngsters from several cities in Canada. There is a waiting list of more of hundred names for additional Homes,and there are now only few admission, in special cases, into Institutions.

There are no sexual problems in the 58 residents cared for by Reena;If they should encounter such problems,they could go for consultations to a very fine Government Centre for developmental problems. But sometimes there occur behavior problems which need quick and resolute decision.Parents involvement is varying :sometimes very marked,sometimes exaggerating and disturbing,sometimes completely lacking - as everywhere else...

On visiting Camp we found 35 clients and 34 workers.In every cabin lived 7 boys or girls with 2-3 counsillors.There is no Government Funding for summercamp in Canada;only donations and parents ' contributions.Some of the residents were quite low in functioning and needed a lot of help.

In Toronto they have running also some special programs for new parents.One is called "Parent Network "where they arrange regular meetings between more experienced and new parents.Another group is called PILOT PARENTS,where matches are made between some new parents and a pair of well versed more experienced parents who went through

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the same problem as the new parents,like Down Syndrom,the same age,the same social upbringing etc.

24) All these facilities we " older " parents did n't have thirty years ago: No Experts for evaluation,no social worker with special understanding,no kindergarden,even just to leave the child for an occasional three hours; no advice how to stimulate and how to play and how to work with the child,and no financial help at all. Therefore we had to fight for everything,if we did n't want to fall into deep despair.

To-day parents take all these big achievments for granted;many don't want to become too involved with these not so pleasant problems, and then,as to-day,there are only the very few who take things seriously,get so deep involved until they can't go out of it anymore and continue to struggle for even better and more comprehensive services.Then as to-day quite a few families get broken up,quite a few husbands run away and quite a few mothers carry the whole responsibility on their shoulders and struggle along the via dolorosa, not without loosing quite a bit of their previous attractive personality.

25) When I wrote in the fall of 1981 to Prof,Dybwad that I intend to visit facilities in the States,he suggested that I make a point to visit MACOMB-OAKLAND CENTRE in Michigan.

I am most grateful for this suggestion,because I did not hear before about their work,and now I was priviliged to spend two days there.While still at home I could prepare myself on hand of a whole package of printed material they did send me in advance.

Macomb-Oakland Centre is a complex facility serving three counties with two million inhabitants.Their greatness lies not only in moving hundred of clients out of the Institutions,but building up a large number of Grouphomes and Foster-families who look properly after more than 1000 retarded people in all ages.

Originally,about ten years ago,it was planned to build a new great institution according to the needs of this large population served in three counties.When the Grants necessary were late to be released and the needs for placement became urgent,it occurred to the people in charge of the project that perhaps they could find some families which would be willing and capable to take in a needy person with the promise that they would not only be trained for this new job,but were also to receive continuous help whenever they asked for it. Thus only a small facility for 90 people was built on the spot,and gradually more foster families were found and some group homes were built up in various areas of the counties.

This task was made easier by the good educational facilities

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of the State of Michigan in which to-day obligatory school systems from age sero to 26 years exist.Autistic children,too,are integrated and are also provided with some group homes,as their parents don't like them to mix with other clients, maintaining that they are not suffering from M.Ret.

26) This Centre is staffed by 250 professionals;5oo people are working in fosterhomes and 6oo more are responsible for group-homes. Here,too,I heard complaints that up to recently the whole complex of Mental Retardation is still poorly taught in some University schools for physicians,teachers and social workers,and that too many of those professional workers keep still to old-fashioned opinions,like advocating segregation,and this inspite of the great progress that has been made in all aspects of diagnosis,treatment, stimulation and prevention.Here in the States as everywhere else it is not so much new and better research that we need,but a much better and wider distribution of the knowledge and the techniques which are already available and have been tested over and over again.

I would dare and say that in only 5 % of all the thousands of counties excellent facilities do exist;in another I5 % of counties people in charge do know what should be done and strive to achieve it;but in most of the remaining rural counties many of the progressive laws - like 94/I42 - are still a dead letter and thousands of parents have not yet heard about them. This situation is world wide and not limited to the States.Still,when visiting a such progressive place like this Centre you can'thelp wondering why only the people in these three counties are priviliged to excellent services and what are the crimes of ten thousands of people in hundred of other counties that such or similar services are detained from them ! Even to-day it should be the main task of the Associations for ret.people to achieve a better distribution of adaequate services after so many excellent pilot programs have proved beyond doubt their value.and so many people are served properly here and there.

27) Naturally I cannot judge the actual quality of services offered by this unique centre in Michigan although I made a visit to a fosterhome of a Down syndrome boy who was cared for by an elderly lady like her own child in best possible physical conditions and a warm relationship.Still,I got quite a good impression about the prevailing atmosphere through the talks I had with eight staff people whilst we were discussing all kinds of topics,like

a)the screening procedure for contracting new foster parents.This is the sole job of four social workers !

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About twenty parents apply and are interviewed until finally one family is contracted !

b) The licensing procedure for grouphomes according to a very rigid Codex of the Depart.for Mental Health.

c) The training procedure for new foster parents,the review workshops which must be taken by actual foster parents,the always available expert help,day and night,in all difficult situations;

d) The expertise neveessary to match available foster parents to the right kind of retarded or physically severely impaired child ; and the knowledge available to exactly teach each foster parent the anti choking device or other techniques of feeding,sitting up etc. neccessary for keeping children in total care !

e) The transfers deemed neccessary to be made after 3 or 4 years when it is felt that a child has outgrown the educational potential of his family and a higher functioning family should be found for him.

f) The hughe energetic efforts -financial,organisational and educational- neccessary in order to develop each year some 2c new group homes !

g) The voluntary Parents Monitoring Committee which is permitted and has to visit each month 4 - 8 group homes without previous annouuncement; it meets every month with the Director and prepares detailed Reports about its findings.I asked to meet the Chairman of this Committee,Mrs Taylor, because I was so impressed after reading an account of their work. At every visit two members take part;they look into all details,according to a questionaire and not only into details which were mentioned in any complaint.Usually they visit at dinner time,between 5-7 p.m. or in the evening.Sometimes they find that there is not enough staff on duty or the meals are not O.K. ;or the doors are not locked properly or the social worker takes his task too easy.One admistrator may be in charge of three or more group homes.Mrs.Taylor will not visit homes which are under the responsibility of the same administrator of the home in which her son lives.

h) The thick handbooks which give advice and orders for every possible situation;this is a State Agency where heavy personal responsibility falls on each worker, but still enough freedom must be left for individual initiative without which no intelligent person would agree to invest his efforts.

I could continue to write pages and pages about their work;but this is not my task;they have done this much better;interested readers are invited to visit there or ask for their printed material.

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28) Half a day at Detroit I visited at the Jewish Assoc.for Retarded Citizen who have established up to now six group homes.Some were bought with donations,three are leased from the builders who in turn have a contract with the State of Michigan.In each Home somebody is living in.(In two homes couples with children.) Most of the staff is not Jewish. I visited with the energetic Director,Miss Joyce Keller, two beautiful furnished homes.All the residents go to workshops and club facilities managed by the Jewish Vocational Service and the Community.

In one home visited all the residents were not verbal.By law two councillors must be present always during the day.Miss Keller thinks that it is better to have for higher functioning retarded people sex seperated flats because the interests and hobbies of men and women vary widely.She said that they nearly don't have sex problems. The social worker of the Assoc.does a lot of follow_up work,also according to telephone calls;referrals,home visits,crisis intervention. Since January 82 there have mananaged to establish six Citizen Advocacies.There are I5oo members on their mailing list and I20 on the waiting list for group homes.

29) When I visited CAMP WABAN in County of York,Maine in I972 after the Congress in Montreal,I had read something about their work in the Paper of the N.A.R.C. When I left Camp Waban a week later, I was infected with their enthusiasm and unique way to establish a summer camp in the forest near the lake,utilising modern play therapy for retarded children of all ages.

Therefore there was no doubt in my mind that on this trip,too,Imust visit my friends Carolyn and Wayne Wormwood and Irene Allen. However,I was touched unpleasantly when I learned that they had left Camp Waban in I976 ,after spending there some of the best years of their life - developing new services,building a whole community out of nothing and earning the whole hearted support of Southern Maine.

Explained Wayne W.to me:Public schools suddenly got all the funds, because they joined "Mainstreaming ".In reality they don't prepare retarded children for work or for life.But the parents of many children enjoy the illusion of mainstreaming (Exuse me,Kay Stambler in Burlington,Vermont;Sandford is not so far away from Burlington; please go there and find out for yourself and let me know !) and think that now their children aren't anymore retarded,and therefore they don't need anymore a summer camp or special services !

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Wayne Wormwood just got tired to ask hat in hand for money and grant; which previously had been given in a nice way; so he quit.

Camp Waban has now a new Director. Instead of the 250 and more who came for Camp eight years ago, they are now only 75. And some serious selection takes place too, because children with behavior proble aren't accepted anymore....

3o) Summary of important impressions.

I) The hughe size of the Continent makes it possible for a big variety of levels of activity to co-exist at the same time in different places: Excellent services, Good services, poor services and no services at all. Therefore: Everything what somebody tells about the U.S., might be true, because no single person might be sure he has seen all kinds of services.

2) The technical standard (space, equipment, cleanliness) of the Institutions for the retarded has surely improved, although even as recently as I977 severe accusations were heard in the court against an institution in Michigan - which is due to close its doors in I983.

3) There exists an energetic trend to take people out from the institutions and to look properly after them in the community.

4) This trend brings neccessarily with it the enlargement and improvement of community based support services.

5) At the same time there is a definite slowdown in new placements into institutions.

6) There exists a strong impact of Federal Grants matched with State Grants utilised and carried out by County Services. All this brings with it stronger professional supervision and safeguards for higher quality of services than it would be the case, if every small Municipality (as in Israel) is in charge of providing community-based services.

7) There exists a big reservoir of highly trained specialists in all branches of work with the retarded, except a shortage of Physiotherapists.

8) Everywhere in the States it is quite easy to get a flat or a house: This enables great mobility and flexebility in developing new services in new areas.

9) There exists a strong awareness to fight for better laws which in turn permit to give the retarded better services. There is quite a good technique in order to get Grants, even when this year some rigorous cutting down takes place in many places.

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Io) All this is achieved by fruitful cooperation between devoted and outstanding parents leaders and not less devoted and outstanding professional and administrative experts in regional Assoc. for the Re

II) The important work of Wolfensberger starting I5 years ago in Ohama - Nebraska, expanding in Toronto during the early seventies and continuing now in Syrac use in developing Citizen Advocacy, Normalisation and Pass workshops has had a profound influence on the whole scene, although he himself is rather pessimistic to-day when he looks on the daily life in our communities through his social microscope.

I2)One of the weaker points seem to be the workshops: Not only that there are not enough of them; that they are lacking leadership; neglect to give their clients a richer selection of academic skills and don't work enough with the parents; they have difficulty to get t right kind of work and do not develop their own production lines which would enable them to give their clients better payment. To-day they pay 2o -8o cents an hour which means exploitation and surely does not act as an incentive for improving work quality and quantity which are prerogatives for later placement in outside jobs.

I3) In contrast to the mass sterilisation carried out in thousand of clients in the institutions in the early sixties and early sevent to-day the trend is in the opposite direction: The stress is on citizens rights and the need of court agreement for each individual case.

I4) The retarded are not automatically at age I8 or 2I put under a guardianship; only if the parents ask for it. Everyone receives his Sosial Security benefits and Mediced as a citizen as long as he has no more than $ I5oo. in his Bank Conto.

I5) In contrast to everyday life in Israel exist in the U.S. four fundamental amenities which have a profound influence on all the social life and community activities there (although the people in the States take these things for granted):

a) Nearly everybody has his own car; in a family there will surely be at least two cars.

b) Everyone has a telephone which never breaks down. If you move into a new flat or a new house far away in the woods: Within three days you get your new telephone.

c) Nearly everybody has two full holidays every week, Saturday and Sunday.

d) All people in jobs have a good income which enables them to take part in weekend workshops or Conventions in big Hotels, if they wish to do so a few times in the year.

These four amenities enable a much stronger activity of parents,

professionals and other interested people in all aspects of cultural life,and naturally also with regards to their involvement in matters concerning M.R.

I6) Nevertheless,under the much more difficult conditions of life in Israel we have made good progress in most areas and hopefully,inspite of severe local economic restrictions during the last years we will continue to improve our Services for the retarded and the handicapped.

I7) I am aware that I may have made mistakes in taking down my notes or may have misunderstood what has been said to me.I beg therefore all persons involved to excuse my mistakes or any misstatements which may have been made by me without any bad intention.

I8) I also beg for forgiveness by all those who have spent time with me and have explained things,but their name has not been mentioned in this report.

I have written this text all by myself,and as I have not learned English or type-writting,therefore this work is also done by a non-professional !

I9) Naturally,I am looking forward to receive your positive or negative remarks on this Report.

20) As an addition I add here some Notes about

ACTIVITIES FOR THE MENTALLY RETARDED IN ISRAEL.

I)

Israel has a population of four million people,and 70,000 children are born each year.

At least 3% or 2Ioo of these will suffer from mild M.R.and hopefully most of these will visit special schools who are under the responsibility of the Ministry of Education.Later on most of them will manage to enter the mainstream of life,quite a few also will be able to enter military Service and later get married.

½ % = 350 children are born each year suffering from medium Retardation and 0,I % = 70 shall suffer from severe Retar. For them the M.R.Authority in the Ministry of Social affairs takes responsibility.

If we take into account a period of 30 years,then we have in the country ca. 9000 such people,most of them are registered and served.

2) There exist ten Governm.Institutions,each with I5o to 4oo persons. Total : 3000 persons.

" " ten public not profit Institt.,each with 30 to 80 clients, Total : 450 persons.

" " I8 private Institt.,each with 35 to I8o clients, Total I65o clients

Total in Institutions : 5I00 "

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3) We have 20 Infant development and stimulation day care centre, for the one to six years old 300 children

We have 60 special schools for the medium Retarded, organised togeth with Ministry of Educ. and local Authorities, for age of 6 to I5 y. which are well spread over the country, including rural areas with I200 children.

We have 40 workshops for age of I5 to 60 y., all rum by local authorities and supervised by the M.R.Authority I500 Students.

8 Hostels (Group Homes for I2 to 25 people, age I8 to 55 y. mostly run by Akim I20 Residents.

5 group flats in ordinary Dwelling houses, each for 4 to 6 people 25 Residents

I2o Foster families with I to 4 children each I80 children

IO Foster families with 5 to I2 children each I00 " "

Total living in the Community: 4000 People

We have also 30 activity Clubs, open 2 to 5 times a week, serving ca Iooo people, run mostly by AKIM with small Government subvention.

a Holiday Camp, run by AKIM, for four groups of 25o children, each group for 6-7 days, 75% financed by Government.

4) There exist 3 Diagnostic Centres for age 5 and more, run by the M.R.Authr., which see in the Year ca I000 children and advise about their placement.

There exist now also IO Development Clinics on behalf of the Ministry of Health for age zero to 5, mainly for diagnostic work, but lately doing also some stimulation work with AKIM financing it. They see each year ca 25oo children, many not really retarded.

5) The Ministry of social welfare has in recent years developed three seminars for nurses working in Institut. for retarded. The course takes 9 months, and they turn out each year ca 7o nurses.

The courses in Teacher Seminars take 2 or 3 years.

Ordinary school starts at 7 or 8 o'clock and finishes at I o8clock. High School starts at 7 or 8 and finishes at i or two. Special school for mediate retard. children starts at 8 and finishes at 3 or four; the same with workshops.

Most of the figures of placement etc. I received by courtesy of M.R.Authority.

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6) A K I M, Israeli Association for the rehabilitation of ment. retarded citizens, was founded in 1950 by three small groups of parents and volunteers in Jerusalem, Tel-Aviw and Haifa. To-day we have 45 branches, but only a part of them run services. Up till now our policy was to establish pilot projects and new services and then to turn these over to local Authorities which by law are in charge of all educational and social services. Now we think twice about it, due to cuts in grants and unsufficient quality of staff employed here and there.

7) 20 years ago we founded the first four workshops. Only one of these is still managed by us.
15 years ago we founded the first summer Camp.
10 years ago we established the first six Clubs.
6 years ago we founded the first four Hostels which are still all run by us, with Governm. payment.
4 years ago we founded the first Infant stimulat. Centre.
3 years ago we founded a Guardianship Association which up till now has found 150 volunt. Guardians.
In most Institutions we have active Parents Committees who act as watch dogs and collect donations for improved additional service.

8) We begin to think about appropriate solutions for the elderly retarded. We have an own Staff of social workers and other experts who help the local branches of the Organisation in developing better services for the retarded and their parents. We are especially interested in establishing groups of parents for discussing common and personal problems.

We are struggling, not very successfully, with Ministers, parlamential committees and regulators for a better quality of educational and other needed professional services. In particular we have great difficulties in convincing the Officials of Local Authorities that better services for our children make also better citizen of our parents, or with other words:

_SERVICES _FOR_THE_ POOR_ ARE _POOR _SERVICES;_

We believe that WE NEED INDIVIDUAL SOLUTIONS FOR SPECIFIC PROBLEMS;

We know that THE PARENTS ARE IN SEVERE NEED OF HELP,

UNDERSTANDING, EDUCATION AND STIMULATION, NOT LESS THAN THEIR CHILDREN;

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I?) _Social SeCURITY_ pays now for every retarded and certified child from three years onwards a monthly invalid benefit. If the child lives with his parents, they get all the money; if the child lives in an institution, only 20 % of the rent is paid out to the parents, 50 % go back to the M.Ret.Authority and 30 % go to a special Fund for improved services and other amenities. The fund is managed by a joint Committee a every Institution or Group Home can submit each year projects for appro The sum is allocated according to the number of children cared for at each place.

II) AKIM is arranging together with the Departments of Education and social work of some Israeli Universities a few times each year some workshop[s], each one dedicated to a specific topic. So we had a Conference for parents of age zero to five, and another workshop for parents of adult retarded: In spring we celebrated the 30.anniversary of Akim with a most impressive evening in a Tel Awiw Theatre called HEARTS and FLOWERS : 12 dancing and reciting and singing play-groups of different Institutions, workshops and Clubs performed before a surprised and deeply impressed crowd of parents and ordinary public: Nobody did believe that such an interesting program could be created by the Retarded !

I2) In conclusion : Over the last 25 years we have made substant progress; but there is still so much to improve and achieve, and there still is so much to fight for things which most other citizens get without effort and by right , that we need another generation of very devoted parents and volunteers. We are looking for them and hope they will be forthcoming...

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